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**State of Rhode Island**

**Department of Human Services**

**Center for Child and Family Health**

**TECHNICAL RESOURCE DOCUMENTS**

**Providers of Personal Assistance Services and Supports  
(PASS)**

**PUBLIC DRAFT FOR PUBLIC COMMENT**

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## RESOURCE A: SAMPLE ASSESSMENT AND SERVICE PLAN

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**Child:** Margaret Smith (DOB – 3/20/95) – 8 years old

**Diagnosis** Mental Retardation (unknown cause) – difficult to test, but IQ falls between 30 and 40 with many splinter skills, ADHD combined type, expressive and receptive language disorder.

**Date of Plan:** 9/10/03

### PART A: ASSESSMENT OF FAMILY CIRCUMSTANCE and PREPAREDNESS

#### I. Relationships:

- a) **Family** - Margaret lives in Cumberland with her mother, Marie; her father, Richard; sister, Jean (9); and brother, Jack (6). Extended family all live out of state, but Margaret accompanies family to visit relatives several times a year.
- b) **Friends** – Margaret knows many of her brothers' and sisters' neighborhood friends by name and they know her, especially Jesse, Justin, Chris (Jack's friends) and Lacey, Karen and Sarah (Jean's friends). These children frequent the Smith household and neighborhood play areas. Although never unkind, these acquaintances don't always seem to know how to include Margaret in their play. Margaret enjoys her classmates at Broad Street School. She knows children in her self-contained class, but also other typical grade level classmates from inclusion phys Ed, library class, music, art, and recess. She knows a few of the children in her Sunday school class at church.
- c) **Other Service Providers** – Margaret is in a self-contained special Ed classroom at Broad Street Elementary with inclusion classes as described above. She requires the assistance of a one-on-one aide at school to provide behavioral cues and redirection at a fairly high frequency throughout the day in all settings. She also receives speech therapy, OT and Adaptive Phys Ed. through school. The Smith's receive a few hours a month of respite service.

#### II. Personal Resources

##### What works for Margaret:

- Loves interacting with people – kids or adults (needs “interpreter” who understands her limited speech)
- Loves tennis or other net sports (watching TV or live, or participating as she can)
- Likes to “swim” (play in the pool)
- Likes baseball (watching), kickball (playing)
- Likes swinging
- Likes TV – Sesame Street, Tennis, favorite videos
- Likes letter identification games on the computer
- Does better when activities are structured
- Needs to keep physically active

- Likes music – hearing it, being around it (children’s choir at church)

**What doesn’t work for Margaret:**

- Great difficulty with motor planning and coordination
- Hates fine motor tasks (crafts, gluing, pasting, etc.)
- Most people do not understand her limited speech (needs “interpreter”)
- Certain loud noises (fireworks, babies crying) are aversive to Margaret
- Busy, chaotic, noisy environments can be overwhelming
- Margaret hates waiting and “down time” – sitting still
- Frustration can sometimes lead to aggression (pinching or hair-pulling)

**III. Respect**

| Positive Qualities   | Qualities often leading to rejection  |
|--|---|
| <ul style="list-style-type: none"> <li>• Cheerful, smiles all the time</li> <li>• Accepting of ALL others</li> <li>• Friendly</li> <li>• Wants to please</li> <li>• Concern for others</li> <li>• Energetic</li> <li>• Happy and joyful</li> </ul> | <ul style="list-style-type: none"> <li>• Limited unintelligible speech</li> <li>• Repetitiveness in communication</li> <li>• Impulsivity – tends to interrupt, not wait for turn, walk in front of swings, cross street without looking, etc.</li> <li>• Short attention span (few seconds)</li> <li>• Occasional pinching or hair-pulling when frustrated</li> <li>• Lacks coordination for many childhood activities</li> <li>• Sucks on fingers, objects (other kids get grossed out)</li> </ul> |

**IV. Choices**

| Made by Margaret  | Made by others  |
|---|---|
| <ul style="list-style-type: none"> <li>• Food choices from array offered by family</li> <li>• Videotapes</li> <li>• Books to be read</li> </ul> | <ul style="list-style-type: none"> <li>• Clothing to wear</li> <li>• Wake up and bed time</li> <li>• Menu offered</li> <li>• School activities</li> <li>• When to go out</li> <li>• Where to go when out</li> <li>• Who to stop and talk/play with</li> </ul> |

Margaret could be offered some structured choices about what she wants to do with non-TV leisure time, e.g. “would you rather find some kids to play tennis or go to the park for a swing?”

## V. Home/Other environments

| What works?  | What doesn't work?   |
|--|--|
| <ul style="list-style-type: none"><li>• Dedicated parents willing to do what it takes to care for Margaret</li><li>• Parents dress, undress, bathe and toilet Margaret due to her coordination problems</li><li>• Parents committed to including Margaret in all typical activities of the family, neighborhood and community.</li><li>• Parents and sibs good at interpreting Margaret's speech</li><li>• Caring sibs</li><li>• Neighborhood kids are pleasant</li><li>• TV keeps Margaret engaged and happy (tennis or favorite videos)</li><li>• Food cut into small pieces – close monitoring for proper pacing during eating.</li></ul> | <ul style="list-style-type: none"><li>• Parents are stretched between meeting Margaret's intense needs and needs of other sibs.</li><li>• Attending "family" functions – scouts, school, church – parents need total focus on Margaret, can't participate in function</li><li>• Margaret wants to engage with EVERY person, stranger or not (still rides in supermarket carriage to prevent this – soon too big)</li><li>• Larger crowds are difficult</li><li>• Other than TV, Margaret doesn't self-entertain constructively– needs constant supervision/engagement at all times</li><li>• Unmonitored, Margaret will stuff during eating, swallowing food items whole (has needed Heimlich)</li></ul> |

## VI. Communication (Optional)

Communication is a major concern for Margaret

| What works for Margaret?  | What Doesn't Work for Margaret?   |
|---|---|
| <ul style="list-style-type: none"><li>• She wants to communicate</li><li>• She is VERY persistent and creative in her attempts</li><li>• Many of her words are intelligible</li><li>• She uses gestures and signs to clarify her meaning</li><li>• She will respond to "20 questions" when listeners are unsure what she means</li><li>• Having a parent or sib to interpret for her to those not used to her speech</li><li>• She has become familiar with computer keyboard and knows letters and their associated sounds</li></ul> | <ul style="list-style-type: none"><li>• MANY of her words are unintelligible to those who don't know her well.</li><li>• She can not string words together into sentences</li><li>• When she cannot make her meaning understood, she whines repeatedly.</li><li>• Often her inability to communicate results in frustration and aggression.</li></ul> |

Margaret's school team feels she is a good candidate for an electronic communication device. They will be exploring various devices during this school year.

## **VII. Health (Optional)**

No unusual health concerns for Margaret

## **VIII. Daily Routine**

**7:30 AM** – Mom or Dad waken Margaret and other children. One parent oversees sibs getting ready for school. Other parent takes Margaret to bathroom, dresses her, and brushes her teeth, hair.

**8:00 AM** –Margaret watches TV. One parent prepares simple breakfast. Other makes lunches. One parent writes note to Margaret's teacher. Other monitors Margaret's breakfast and gives meds. 8:10 special bus arrives for Margaret. Sibs go to corner for regular bus.

**Parents quickly shower and off to work by 8:45 – Mom home from work at 3PM.**

**3:15 PM** – Margaret's special bus arrives home from school. Mom greets her. Takes her to bathroom. Reads note from teacher. Margaret watches TV. Mom prepares a snack, monitors Margaret eating snack.

**3:30 PM** – Sibs arrive home from school. Get own snack. Relax for a few minutes. Go out to play. Margaret starts to whine. She wants to go out too.

**4:00 PM** – Mom takes Margaret out to walk around neighborhood. Find some kids playing ball at town garage (Jack is with them). Watch the kick ball game and participate for a while.

**4:30 PM** – Mom says time to go home and get dinner ready. Margaret balks, refuses to walk, attempts to bite Mom. Mom carries across street. Makes sure doors are closed tightly so Margaret doesn't go back out (Margaret can't turn door knobs). Once home in front of TV Margaret is happy. Mom can start dinner.

**5:00 PM** – Initial dinner preparations over. Mom takes Margaret to the bathroom, and then works with Margaret on homework (ten minutes or so) TV back on. Sibs come in from playing. Want something else on TV. Margaret whines. Sibs angry; go off to play computer upstairs.

**5:30 PM** – Dad home. Dinner. Dad cuts up Margaret's dinner and monitors intake. He eats his dinner after Margaret is finished (in 3 to 4 minutes or less – even monitored Margaret eats VERY fast). Margaret goes back to TV. Mom, Dad and sibs review day. Margaret intermittently comes back and attempts to grab food from other's plates.

**6:00 PM** – Mom takes Margaret to bathroom. Then Dad takes Margaret and Jack to town playground at Monastery. Mom and Jean clean up from dinner. Jean, who elected to stay home, starts on homework.

**6:30 PM** – Dad keeps close eye on Margaret so she doesn't run in front of swings; interprets her constant attempts to interact; keeps her from becoming annoying with repetitiveness or aggression with other children. Jack plays without a lot of adult interaction.

**7:00 PM** – Dad and kids come home. Mom bathes Margaret and dresses her for bed. Dad oversees Jack's homework.

**7:30 PM** – Margaret has her favorite "night snack," ice cream. Mom brushes her teeth. Reads her a story. Puts on her favorite CD to go to sleep. Asleep by 8PM.

**8:00 PM** – Dad oversees Jack's bath. Jack and Jean have some ice cream with Mom and Dad. (The Smith's have developed this routine of Margaret going to bed earlier even than Jack, her younger brother, so the two typical sibs have some time when Mom and Dad can focus on them without the distraction of constant supervision of Margaret).

**8:30 PM** – Jean takes her bath. Mom reads to Jack.

**9:00 PM** – Jack to bed. Mom reads to Jean.

**9:30 PM** - Jean to bed.

**Analysis** - The Smiths identified after school time as a time when extra supports are needed, especially to support Margaret in play activities that other children her age can do independently. They also feel that an extra pair of eyes and hands to monitor Margaret during dinner would free them up as parents to lead a more typical family dinner time, rather than focusing solely on Margaret during this time. Likewise, assistance with Margaret after dinner, but before bedtime would allow the Smiths to attend to the needs of all three of their children equally.

## **IX. What does Margaret need to learn about...**

### **a) Social Roles and Social Settings**

- Make some friends among the neighborhood children
- Learn turn-taking in games with neighborhood children
- Learn better turn-taking in conversation (will need interpretation until [if] she learns communication system that unfamiliar listeners can understand)

### **b) Safety and Self-Preserving Decisions**

- Learn not to approach or greet strangers
- Distinguish between food and non-food items BEFORE she puts them in her mouth

- Practice safe street-crossing and playground safety with help

**c) Activities of Daily Living**

- When eating – take small bites, chew and swallow before next bite; use utensils, not hands
- Learn other safe ways to amuse self when at home besides TV (maybe books on tape, expand computer use??)
- Learn some independence in toileting.

**X. What are Learning Opportunities in Margaret’s Community?**

**a) What do her siblings do outside of school hours?**

- They often play on nearby town garage grounds (parking lot and field) pickup games of kickball, four square, baseball, football, roller-skating, etc.
- Jean and Jack both play soccer in the fall with Cumberland Youth Soccer and baseball/softball in the spring with Boys and Girls Club.
- Jean is in the school chorus and band
- Jean is a Girl Scout; Jack a Cub Scout
- Jack occasionally goes with a friend to Boys and Girls Club after school drop in center or to swim.

**b) What do other grade school age children do outside of school hours?**

- Many children stay at B.F. Norton for the after school program there.
- Some children go to the Boys and Girls Club game room, gym and pool.
- Soccer and baseball are big with young kids in town
- Informal play, such as described above at the town garage

**c) What Community Opportunities Match Margaret’s interests, gifts, and capacities? What valued role or contribution would Margaret make in these settings?**

**1) Within walking distance?**

- Informal games at town garage – Margaret could be included in kickball, four square
- Margaret could introduce rackets and balls to town garage parking lot activities for neighborhood pickup “tennis” games.
- Interaction with sibs and their friends when playing at home – board games, card games, tag, dress-ups, etc.
- High Street Market – with guidance, accompany sibs/friends on errands
- High Street Baseball field – watch little league games, learn to be a “spectator”
- Blackstone River Theatre – Musical performances for kids on Sundays – takes tickets?

**2) Within five miles?**

- Boys and Girls Club – Swim in the pool



- Girl Scout Troop - explore joining Jean's troop; meets Tuesdays 6:30 – 8PM
- Playgrounds – Monastery, B.F. Norton School, Ashton School
- Cumberland Library at Monastery – any musical programs for kids, computer activities?
- Siblings sports games (soccer, baseball, softball) – spectator role
- Tucker field – town tennis courts – spectator/ball girl?

## **PART B: GOALS/OBJECTIVES and OUTCOMES in PASS DOMAINS**

### **I. Family's Priorities for Margaret in Home and Community**

The Smiths feel that it is most important to give Margaret lots of opportunities to interact appropriately with other grade school age children so she can have the chance to form friendships. They would like the support of PASS during after school hours at home or in the informal play settings of the neighborhood (town garage and playgrounds) and also by having Margaret join the Girl Scout troop her sister attends. In these settings, Margaret can practice her communication skills, turn taking in conversation as well as cooperation in structured games and activities.

At mealtimes, Margaret needs almost constant “coaching” to moderate the pace of her food intake during meals. The Smiths would like help from PASS in this regard during dinner so the family meal can be a more relaxed experience for all family members.

The Smith's would also like PASS support to “coach” Margaret in alternatives to TV for self-amusement. This can be done on inclement days or after dark.

### **II. Goals and measurable objectives for the next six months**

**Domain A: (Activities of Daily Living) Margaret will begin to learn appropriate and safe pacing of eating her dinner, and begin to develop some independent leisure skills, and improve bathroom independence.**

1. During dinner, with coaching, Margaret will learn to place her utensils on the table and take a sip of water between each bite she takes with 80% success.
2. When other children are not available to play with, Margaret will have mastered at least one activity she can engage in independently (as an alternative to TV). Perhaps books on tape, puzzles, matching cards, computer game, etc.
3. Margaret will tell her assistant when she needs to use the bathroom and will pull down her pants independently for toileting 100% of the time (up from 80%).

**Domain B: (Safety and self-preserving decisions) Margaret will begin to learn and apply safety rules when out in the community (safe stranger behavior, safe street crossing and playground behavior)**

1. In the course of neighborhood activities, Margaret will reduce the number of times she approaches or greets a stranger from an average of five per outing to two or less.
2. Margaret, with coaching every time, will begin to learn to STOP at the curb before crossing street and to STOP and move out in a wide arc before passing in front of swings.

**Domain C: (Social roles and social settings) – Margaret’s amount and type of social interaction with neighborhood children and other social experiences will begin to more closely approximate that of a typical eight year old girl, giving her all the best chances to practice communication and social skills.**

1. Margaret will increase the number of times she participates in neighborhood children’s games (kickball, four square, tag, etc. outdoors or board games, cards, dress-ups, etc. indoors) from one time a week to three or more.
2. Margaret will successfully recruit neighborhood children to play tennis so she can watch and/or play at least twice a month (she will provide them with rackets and balls).
3. Margaret will join her sister’s Girl Scout Troop and participate in the weekly meetings and other activities of the troop.
4. In the course of neighborhood play activities, Margaret will increase the amount of appropriate conversational turn taking from 20 – 30 % to 50% of the time.
5. In the course of neighborhood play activities, incidents of Margaret’s pinching or pulling hair will decrease from three a month to one a month or less.

**Interface with other supports and programs**

Many of these goals are mentioned in Margaret’s IEP. However, due to the nature of the academic setting, there often is not ample enough opportunity to practice these skills at school – e.g., eating, stranger behavior, street crossing, independent leisure activities, etc. The Smith’s will pass on suggested strategies from Margaret’s OT, SPL Clinical Consultant, and teacher. The opportunity PASS provides to practice these strategies frequently in naturally occurring settings in Margaret’s home and neighborhood will greatly enhance her improvement in these areas.

### **III. Relationship of PASS Goals to the expected role of parent/caregiver**

The Smiths will continue to carry out all the expected roles and duties parents of three school age children. In addition they will bathe and dress Margaret; closely monitor all of her eating except for weekday dinners when PASS support will do this; assist Margaret with homework assignments; follow routine to settle her for bed; interact with professionals in Margaret's life to learn best strategies to foster her success academically, behaviorally, socially, and communicatively; apply these strategies with Margaret themselves and pass them on to the PASS support worker; either Mrs. or Mr. Smith will check in on neighborhood activities Margaret is engaging in several times a week as they do their other children; they will offer volunteer support to the Girl Scout Troop to the same degree all parents are requested; they will interact with Troop leader on any specific planning that needs to happen to accommodate Margaret's disability. Additionally, the Smith's will be closely supervising the work of the PASS worker and providing ongoing training as Margaret's needs shift and change over time.

The role of the PASS support worker is to assist and/or coach Margaret in those roles, activities and/or interactions that most typical eight-year-olds can navigate independently without parental support. Without this support, the Smith's TOTAL attention needs to be on Margaret when she is at home and awake, sometimes to the neglect of their other two children. PASS Support is in no way planned to replace the role of parent in Margaret's life. In fact, it will allow the Smiths to be full parents to all three of their children.

### **PART C: INTENSITY, DURATION and SERVICES SCHEDULE**

Margaret's level of impulsivity requires almost constant direction and/or redirection unless she is watching TV. The Smith's feel pulled between this necessary supervision of Margaret and the appropriate level of attention to their other two children. They feel that weekends are doable with both parents home and everyone in a more relaxed mode. They also feel that they have developed a rushed, but workable weekday morning routine. The most difficult times are in the weekday afternoons when Margaret wants to be engaged with sibs or neighborhood kids and Mrs. Smith needs to attend to household chores and dinner preparation.

They also would like to be able to have a more relaxed family dinnertime. With someone supporting Margaret in pacing her food intake, the Smith's could attend to eating their own dinner and engaging all three children in dinner table conversation.

In examining the community opportunities, the Smiths feel that enrolling Margaret in the Girl Scout Troop Jean attends would be another terrific opportunity to enhance Margaret's socialization and appropriate play. They would like PASS support during the meeting hours – Tues. 6:30 – 8PM – since it is not typical for parents to attend these meetings, yet Margaret will need support. The Smiths also would like to participate in

Friday evening family swims at the Boys and Girls Club, but feel they would rather do that without extra assistance.

Therefore, the PASS Plan would allow for the following schedule:

|           |          |                       |
|-----------|----------|-----------------------|
| Monday    | 4 – 7 PM |                       |
| Wednesday | 4 – 7 PM |                       |
| Thursday  | 4 – 7 PM |                       |
| Tuesday   | 4 – 8 PM |                       |
| Friday    | 4 – 6 PM | <b>Total 15 hours</b> |

The Smiths would like occasional flexibility to shift scheduled hours from afternoon to evening if there is an evening family event at school, scouts or church as these are difficult, but not regularly occurring, times when Margaret needs full assistance to participate appropriately and parents' focus may need to be on the other sibs. They understand that the total hours in any given week would not go over fifteen without a corresponding reduction in hours in a preceding or following week.

## **PART D: ROLES AND RESPONSIBILITIES IN DIRECT SERVICES**

### **1) Activities:**

1. After school neighborhood, playground, and/or indoor play activities
2. Girl Scouts Tuesdays 6:30 – 8PM
3. Dinner time
4. Independent leisure activities (not TV).
5. Occasional family events at school, scouts or church

#### **a). Direct Service Worker Roles:**

- Act as interpreter of Margaret's communication attempts with others (especially other neighborhood children)
- Act as a "coach" for Margaret in appropriate social behavior – turn taking in conversation and games, curbing impulsivity, etc.
- Act as a facilitator of Margaret's participation in activity at hand. This will be especially important at Girl Scouts because of variety of potential activities.
- Notice and report to Smiths all signs of blossoming friendships between Margaret and specific children so they might be fostered in other ways – invitations for play dates, etc.
- "Coach" Margaret in safe street crossing and playground safety. Also prompt her to curb her impulse to greet all strangers.
- "Coach" Margaret's proper pacing of food at mealtime – utensil down and drink of water between bites.
- There may be the occasional instance when PASS worker might need to drive Margaret to an event – e.g., library concert or other event that Margaret would enjoy but siblings wouldn't.

- Assist Smiths in monitoring and “coaching” Margaret at occasional family events.
- In partnership with Smiths, constantly look for other opportunities in the community for Margaret to engage with other children her age.
- Through daily checklist/log, record ongoing data related to the goals and objectives.
- Complete time sheets for signature by Smiths and submit to PA in timely fashion.
- Attend monthly meetings with Smiths and PASS Agency to monitor progress on the plan.

**b). Margaret’s Roles**

- Desire to interact with others
- Strong desire to please
- Interest in sports, especially net sports and baseball/kickball
- Response to structure – Girl Scouts and games with “rules” are good settings for her

**c.) Family’s Roles**

- Work on these goals with Margaret in other settings, especially on weekends
- Take Margaret and sibs to Family swim at Boys and Girls Club on Friday evenings.
- Make the appropriate inquiries/preparations with Girl Scouts and register Margaret
- Act as intermediary between school services/goals and goals of PASS, particularly around communication and behavior.
- Drive Jean, Margaret and PASS worker to and from Girl Scouts
- Recruit, train and supervise the PASS worker – especially in Margaret’s “lingo.”
- Jean and Jack will frequently be available as in-home playmates for Margaret.
- Check time sheets for accuracy and sign
- Be available for monthly meetings with PA to monitor progress of PASS Goals

**c). PA’s Roles**

- Monitor hiring, training, and documenting processes
- Promote ongoing training seminars and educational opportunities for families and workers
- Ensure the continuity and quality of care and services through reporting and periodic evaluations as identified in the certification standards
- Provide prompt conflict resolution

**d). Community’s Roles (Potential)**

- Cooperation of neighborhood kids

- Girl Scout Troop Cooperation
- Availability of Playgrounds, Library, Boys and Girls Club, Little League, etc.

## **PART E: IMPLEMENTATION STEPS AND TIMEFRAMES**

### **I. Recruitment Plan**

1. a). Smith's have used three different respite workers who already know Margaret and her siblings. They plan to ask all three of these women if they would be interested in some or all of the PASS hours. Timeline – 9/17/03
2. If this does not result in filling all the necessary hours, they plan to post an advertisement through the special education department at school to all the special Ed teachers and teacher assistants. Timeline – 9/24/03
3. If the second strategy does not work, they will place an advertisement in the Valley Breeze (local newspaper) at the same time informing the PASS Agency of their difficulty in recruiting a worker. Timeline – 10/1/03
4. They will implement any suggested strategies provided by the Family Support Agency. – 10/7/03.

### **II. Personnel activities**

1. PASS Worker(s) will complete all required personnel paperwork no later than one week after family agrees to hire, including:
  - ✓ Criminal background check
  - ✓ Driving Record check
  - ✓ W-4s and other tax documents
  - ✓ Employment eligibility verification
2. PASS Agency will process employee paperwork in a timely fashion

### **III. Training Plan**

1. Once recruited and hired, PASS worker will participate in PASS Agency's required trainings (CPR, child development, etc.)
2. Mrs. Smith will provide the worker a list of the words Margaret says her own way with "translation."
3. Mrs. Smith will devote at least the first week on the job to accompanying Margaret and the worker into all the settings and activities they will frequent. Mrs. Smith will model and comment on the following, among other things:

- “Interpreting” Margaret’s unique combination of words, gestures and behaviors and what Margaret means by them to others (children especially, but adults also).
  - Respectfully answering questions about Margaret raised by other children’s curiosity.
  - Facilitating Margaret’s participation in activities --- even if partial participation
  - Using positive behavior supports which work for Margaret
  - Explaining the limitations for Margaret created by her motor coordination difficulties and how to accommodate them
  - Demonstrate Margaret’s bathroom routine and how to promote more independence.
  - Demonstrate the kind and amount of prompts necessary during eating to prevent choking.
4. The worker will have a chance to try these strategies and techniques while Mrs. Smith observes and gives feedback.
  5. The Smiths will train worker in how to collect and record daily data related to goals – simple checklist regarding what happened during shift.
  6. The Smiths will be available during most shifts for questions and clarifications.
  7. When Margaret’s school team identifies further augmentative communication strategies or a device for Margaret, the worker will receive appropriate training along with the Smiths.
  8. The Smiths, PASS worker, and PASS Agency will participate in monthly meetings to assess progress, discuss any triumphs and/or challenges.

#### **IV. Supervisory Roles of Family and PASS Agency**

##### **1). PASS Agency**

- Assist family with recruitment strategies if initial recruitment efforts fail
- Assist PASS worker with required personnel paperwork
- Process background checks and other paperwork in timely fashion
- Assist family in setting up data collection checklist
- Provide training required by all PASS workers
- Pay worker based on submitted timesheets in timely fashion
- Attend monthly meeting with family and PASS worker to monitor progress on Plan
- Suggest strategies or further resources in areas that are showing little or no improvement.
- Assist Family, as requested, with any difficulties of supervision, disciplining, and/or firing or replacement of worker

## **2). Family**

- Take agreed on steps toward recruitment of worker
- Follow through on recruitment suggestions of PA
- Apprise PA when worker is found and put them in contact with each other
- Train worker in Margaret's specific needs as outlined in training plan (above)
- Develop data collection checklist in collaboration with PA
- Check worker's timesheets for accuracy and sign for submission
- Provide ongoing supervision of worker
- Attend monthly meetings with PA and worker to monitor progress of plan.
- Apprise PA of any unmanageable or unacceptable difficulties experienced with worker
- Apprise PA if worker resigns or gives notice of resignation
- Engage in timely re-recruitment efforts, should worker need to be replaced

## **PART F: SAFETY ARRANGEMENTS**

For Margaret, her complex of disabilities creates several safety considerations:

1) Due to her impulsivity and problems with spatial body awareness it would not be unusual for her to run into the street or in front of a swing, etc. One of the PASS worker's roles will be to be vigilant to ensure that this does not happen and to use every opportunity to coach Margaret in stopping to consider these situations herself. 2) Unsupported, Margaret will approach everyone she sees whether familiar person or stranger. Unsupervised, it would be very simple for someone with devious purposes to abduct her with Margaret's own full consent. Again, it is one of the responsibilities of the PASS worker to supervise Margaret's activities very closely to prevent this and furthermore to coach Margaret in distinguishing between acquaintances and strangers and the corresponding appropriate behavior.

2) Margaret can become aggressive when frustrated (her best method of communication of this feeling right now given her limited speech) – she will sometimes pinch and/or pull people's hair. This could be another child or the staff person. The Smith's will be training the PASS worker in how to prevent these occurrences as well as in appropriate consequences for Margaret should they occur, consistent with her positive behavior plan developed by the Smiths and Margaret's school team school.

3) Without monitoring, Margaret will stuff her food during eating sometimes to the point of blocking her airway. Preventing this, again, is one of the goals described above and a duty of the PASS worker to coach Margaret in proper pacing of food intake. Should an airway blockage occur during the family dinner, the Smiths would perform the Heimlich maneuver to dislodge the blockage? The PASS worker, having been trained in CPR, could also do this if either parent was not close at hand.



## **PART G: SIGNED CONTRACTUAL AGREEMENT\***

The purpose of this agreement is to clearly state the responsibilities of the family and PASS Agency to assure everyone understands these responsibilities.

### **Your responsibilities as a Family:**

1. Verify family preparedness to effectively render consumer-directed PASS services.
2. Complete mandatory training provided by the PASS Agency.
3. Work with the PASS Agency to develop the Service Plan.
4. Designate a person who will be the responsible party for the family in decision-making activities with the PASS Agency and in managing the day-to-day work of the PASS worker(s). The designated family supervisor(s) is/are \_\_\_\_\_.
5. Find, interview and hire PASS worker(s). Submit the employment forms package(s) for the PASS worker(s) to the PASS Agency.
6. Train the PASS worker(s) about their job duties and what is expected of them.
7. Develop an emergency back-up plan for coverage when your regular PASS worker(s) is /are absent because of illness, transportation problems or needing time off.
8. Be certain that all hours worked by the PASS worker(s) are within the number of hours approved in the Service Plan.
9. Make sure that the PASS worker(s)' time sheet(s) reaches the PASS Agency on time which is every two weeks. You must complete the time sheet(s) weekly.
10. Review monthly budget reports of the hours worked and paid from the PASS Agency.
11. Assess and document child's progress toward Service Plan goals and objectives
12. Evaluate the PASS worker's performance in accordance with the Service Plan.
13. Contact your Family Support Coordinator when you have questions.
14. Contact your Family Support Coordinator if you have concerns so small problems won't become big problems.
15. Maintain a safe and stable working environment in your home.

16. Follow proper reporting procedures (i.e. incidence reports).

**Your PASS Agency's Responsibilities to you:**

1. Ascertain family preparedness to effectively render consumer-directed PASS services.
2. Provide you with training about the PASS program and modify the training to meet your needs. This includes information about consumer-directed services, Medicaid requirements, recruiting, hiring, discharging and managing PASS Workers.
3. Collaborate with you in the development of the Service Plan.
4. Encourage and support you to independently hire and manage PASS workers. Conduct Background Criminal Investigation (BCI) checks of PASS Workers.
5. Assure proper reporting of hours on timesheets & manage payroll for PASS workers.
6. Talk with you about your satisfaction of the quality of services you are receiving and assure that the PASS worker(s) activities are in accordance with the Service Plan.
7. Be available to you to answer questions or provide technical assistance in resolving problems or conflicts.
8. Work with you to develop a corrective action plan if there are difficulties managing your PASS worker(s).
9. Assure compliance with Federal and State employment laws. Monitor compliance with Medicaid Rules and Regulations.
10. Maintain a case record.
11. Assure proper reporting procedures, i.e. incidence reports.

**What the PASS Agency will not do:**

1. Interview, hire, train, directly supervise or discharge your PASS worker(s).
2. Fill out the employment forms package.
3. Find emergency back up direct service workers for you.

4. Write your PASS Service Plan for you.
5. Approve additional hours beyond those, which are authorized in the current Service Plan.
6. Provide your feedback to the PASS worker(s) regarding their job performance.

**I understand, accept and agree to the responsibilities listed in this agreement and as delineated in the Service Plan**

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**Family Supervisor(s) Signature**

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**Date**

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**Family Supervisor(s) Signature**

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**Date**

---

**PA Staff Signature**

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**Date**

---

**PA Staff Signature**

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**Date**

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**Direct Service Worker Signature**

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**Date**

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**Direct Service Worker Signature**

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**Date**

\* Adapted from "Consumers/Consultant Agreement", Consumers Directed Care Research Project, Florida Agency for Health Care Administration, December 1999

## **RESOURCE B: DIRECT SERVICE WORKER JOB DESCRIPTION TEMPLATE**

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**Job Title: PASS Direct Service Worker**

**Compensation: The PASS Agency agrees to pay the PASS worker \$\_\_\_\_\_per hour.**

The PASS Agency will withhold and send to federal and state governments all unemployment taxes, social security and federal withholdings. A summary of all payroll withholdings (W2 Form) for the previous calendar year will be sent to you by the PASS Agency by January 31<sup>st</sup>.

**Job Duties of the PASS Worker:**

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.
- 8.
- 9.
- 10.

## Work Schedule

**EMPLOYEE START DATE:** \_\_\_\_/\_\_\_\_/\_\_\_\_

The PASS worker's work schedule will be as follows:

Sunday \_\_\_\_ to \_\_\_\_ A.M.; \_\_\_\_ to \_\_\_\_ P.M.; Total \_\_\_\_ hours  
Start time end time Start time end time

Monday \_\_\_\_ to \_\_\_\_ A.M.; \_\_\_\_ to \_\_\_\_ P.M.; Total \_\_\_\_ hours  
Start time end time Start time end time

Tuesday \_\_\_\_ to \_\_\_\_ A.M.; \_\_\_\_ to \_\_\_\_ P.M.; Total \_\_\_\_ hours  
Start time end time Start time end time

Wednesday \_\_\_\_ to \_\_\_\_ A.M.; \_\_\_\_ to \_\_\_\_ P.M.; Total \_\_\_\_ hours  
Start time end time Start time end time

Thursday \_\_\_\_ to \_\_\_\_ A.M.; \_\_\_\_ to \_\_\_\_ P.M.; Total \_\_\_\_ hours  
Start time end time Start time end time

Friday \_\_\_\_ to \_\_\_\_ A.M.; \_\_\_\_ to \_\_\_\_ P.M.; Total \_\_\_\_ hours  
Start time end time Start time end time

Saturday \_\_\_\_ to \_\_\_\_ A.M.; \_\_\_\_ to \_\_\_\_ P.M.; Total \_\_\_\_ hours  
Start time end time Start time end time

**TOTAL** \_\_\_\_ hrs/week

**Responsibilities of the PASS Worker (Please initial):**

I \_\_\_\_\_ agree to report to work on time.

I \_\_\_\_\_ agree to carry out assigned duties and responsibilities as explained to me  
by the Family Supervisor(s) and as written in this agreement and the  
Service Plan.

I \_\_\_\_\_ agree not to do activities unless they are specified in the Individual Service Plan.

I \_\_\_\_\_ agree to accurately document my hours worked and to file appropriate tax  
documents.

I \_\_\_\_\_ agree to assure proper incident reporting.

I \_\_\_\_\_ agree to give feedback to the family designee.

I \_\_\_\_\_ agree to keep progress notes and to give input on the child's progress toward  
Service Plan goals and objectives.

I \_\_\_\_\_ agree to attend and participate in on-going training sponsored by the Family  
Support Agency.

I \_\_\_\_\_ agree to tell the appointed family supervisor(s) two weeks in advance of when I  
need time off and to obtain written approval. This time will be set by mutual  
agreement between the family and me.

I \_\_\_\_\_ agree to call the appointed family supervisor(s) as much ahead of time as  
possible if I am sick or unable to get to work on time due to other problems, e.g.  
car trouble, etc.

I \_\_\_\_\_ understand that I am expected to be reliable.

I \_\_\_\_\_ agree to give the family and the PASS Agency two weeks written  
notice if I decide to end my employment.

**I have read and understand the job duties expected of me.**

\_\_\_\_\_  
Signature of PASS Worker(s)

\_\_\_\_\_  
DATE

\_\_\_\_\_  
Signature of PASS Worker(s)

\_\_\_\_\_  
DATE

\_\_\_\_\_  
Signature of PASS Agency

\_\_\_\_\_  
DATE

## RESOURCE C: CUEING

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Using words as cues is a way to tell the child how to do a specific behavior. For example, telling a child to put on their pants before putting on their shoes. These verbal cues can only be used with children who are able to understand the words being used.

Gestures are the use of nonverbal cues to direct the child to do something. Pointing is a common gesture used. In order for gestures to be used as effective cues, the child must have an understanding of what the specific gestures means.

Modeling is a cue in which the desired behavior is actually demonstration for the child. The use of modeling assumes that the child has reached a certain cognitive level of development that allows him/her to imitate the behavior of others.

Physical prompts as cues involve touches that direct the child's behavior, e.g. touching a child's lips to cue the behavior of closing his/her mouth while chewing.

Hand -over-hand assistance requires the person doing the cueing to place their hands over the child's hands and leading the child through the activity. This requires that the adult be very close to the child and facing in the same direction.

Cues must be faded or gradually tapered off. If this doesn't occur, the child will remain dependent on the cues. Fading or tapering off can be accomplished by pairing less intrusive cues with more intrusive cues and the gradually withdrawing the more intrusive cues e.g. pairing verbal cues with hand-over-hand assistance and gradually withdrawing the hand-over-hand assistance. Fading can also occur by gradually decreasing the intensity of the cue, e.g. the loudness (intensity) of voice in verbal cueing can progress from loud to soft.



## **RESOURCE D: ABILITY TO ACCOMPLISH/PERFORM ESSENTIAL ACTIVITIES OF DAILY LIFE AND AGE APPROPRIATE BEHAVIORS**

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- For newborns and infants (birth to attainment of age 1): Being able to recognize their own body's signals (e.g., hunger, pain, discomfort), and to alert their caregivers of their needs (e.g., by crying). As they mature, their capacity for self-consolation should expand to include rhythmic behaviors (e.g. rocking).
- Older infants and toddlers (age 1 to attainment of age 3): They should be trying to do more things for themselves that increase their sense of independence and competence in their environment. They should be able to console themselves by carrying a favorite blanket with them. Learn how to cooperate with caregivers when they take care of their physical needs but also want to show what they can do; e.g., pointing to the bathroom, pulling off their coat etc.
- Preschool children (age 3 to attainment of age 6): They should want to take care of many of their physical needs by themselves (e.g. putting on their shoes, getting a snack) and also want to try doing some things that they cannot do fully (e.g. tying their shoes, climbing on a chair to reach something high, taking a bath).
- School-age children (age 6 to attainment of age 12): Increasingly showing independence in most day-to-day activities (e.g., dressing and bathing themselves) although they may still need to be reminded sometimes to do this routinely.
- Adolescents (age 12 to attainment of age 18): They should feel more independent from others and should be increasingly independent in all of their day-to-day activities such as using transportation, handling money and negotiating public places.

\*Social Security Administration, 20 CFR PART 404 and 416, RIN 0960-AF40, Supplemental Security Income; Determining Disability for a Child Under Age 18

## **RESOURCE E: ABILITY TO MAKE SELF-PRESERVING DECISIONS AGE APPROPRIATE BEHAVIORS**

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- For Newborns and infants (birth to attainment of age 1): Being able to console themselves (e.g., by sucking on their hand) until help comes. Responding to internal cues that alert them that they need help.
- Older infants and toddlers (age 1 to attainment of age 3): They should be trying to do more things for themselves that increase their sense of independence and competence in their environment. They should be experimenting with their independence by showing some degree of contrariness (e.g., “No, No”) and Identity (e.g., hoarding their toys).
- Preschool children (age 3 to attainment of age 6): Early in this age range, it may be easy for them to agree to do what their caregiver asks. Later, it may be difficult for them because they want to do things their own way or not at all. These changes usually mean that they are more confident about their ideas and what they are able to do. They should also begin to understand how to control behaviors that are not good for them (e.g. crossing the street without an adult).
- School-age children (age 6 to attainment of age 12): They should begin to develop understanding of what is right and wrong, and what is acceptable and unacceptable behavior. They should begin to demonstrate consistent control over their behavior, and should be able to avoid behaviors that are unsafe or otherwise not good for them.
- Adolescents (age 12 to attainment of age 18): They may sometimes experience confusion in the way they feel about how to cope with stress and changes in their environment. However they have emerging confidence in how to appropriately alleviate stress and make self-preserving decisions. Older adolescents should gradually become their own decision makers. They should learn about the various details of managing their own health care.

\*Social Security Administration, 20 CFR PART 404 and 416, RIN 0960-AF40, Supplemental Security Income; Determining Disability for a Child Under Age 18

## **RESOURCE F: ABILITY TO PARTICIPATE IN SOCIAL ROLES AND SOCIAL SETTINGS**

### **AGE APPROPRIATE BEHAVIORS**

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- For newborns and young infants (birth to attainment of age 1): Respond visually and vocally to caregivers and eventually use gestures and vocalizations to affect others.
- Older infants and toddlers (age 1 to attainment of age 3): Initiate and maintain interactions with adults and play alongside and eventually interact with other children their age.
- Preschool children (age 3 to attainment of age 6): Socialize with children as well as adults and are able to begin to start friendships with other children. They should also be able to use words instead of actions to express themselves, and be better able to share, show affection and offer to help.
- Adolescents (age 12 to attainment of age 18): Initiate and develop friendships and begin to solve conflicts between themselves and their peers or family members or adults outside the family. They should be able to intelligibly express their feelings, ask for assistance in getting their needs met, seek information, describe events and tell stories in all kinds of environments and with all kinds of people.

In assessing a child or adolescent's ability to participate in social roles and social settings in a developmentally appropriate manner, it is important to take a strength-based approach. Examples of areas that might be assessed include:

- Ability to make friends, spend time with them, and engage in group activities
- Make decisions and act independently or to ask for help when either are developmentally appropriate
- The degree to which they sustain attention and use their full abilities to work on tasks and complete them
- Modulate anxiety, depression or hostility when confronted with social situations or task activities that may become frustrating or difficult
- Engage in rather than withdraw from social situations

\*Social Security Administration, 20 CFR PART 404 and 416, RIN 0960-AF40, Supplemental Security Income; Determining Disability for a Child Under Age 18

## **RESOURCE G: CEDARR FAMILY CENTERS**

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- 1. About Families  
CEDARR Family Center  
203 Concord St. Suite 335  
Pawtucket, RI 02860  
  
401-365-6855**
  
- 2. Families First CEDARR  
Hasbro Children's Hospital  
593 Eddy Street, Room 120  
Providence, RI 02903  
  
401-444-7703**
  
- 3. Family Solutions CEDARR  
134 Thurbers Avenue, Suite 102  
Providence, RI 02905  
  
401-461-3251**

**\*Note: Additional CEDARR Family Centers may be certified periodically.**

## RESOURCE H: DOCUMENTATION GUIDELINES FOR PASS

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### I. Documentation Requirements

A. PASS Agencies are required to keep all records necessary to fully disclose the nature and extent of the services provided to children receiving PASS. PASS Agencies must furnish to DHS, its agents and/or the Medicaid Fraud Control Unit of the Attorney General's Office such records and any other information regarding payments for claimed or services rendered that may be requested. These guidelines are applicable to all children receiving PASS services authorized by DHS.

The following are the basic principles of documentation. They apply to all types of services.

1. The client record should be complete and legible.
2. The documentation of each client encounter should include or provide resource to:
  - a) The date, time and units of PASS services delivered with a corresponding number of hours that were billed to Medicaid, legible identity/credentials of person providing the PASS services, (i.e. Clinical Consultant, Family Support Coordinator and PASS worker)
  - b) All time sheets for the PASS worker must be co-signed by the family

B. Each PASS Agency is responsible for devising a system that documents those services that have been provided. This back-up information is usually contained in the client record, daily log, or both and must be sufficiently detailed to show that a client received a specific number of hours of services on a certain day.

C. All PASS Direct Services Care must be provided in accordance with the PASS Service Plan.

D. Methods of Documentation:

The PA Clinical Consultant must enter a discharge summary into the client record within 2 weeks after discharge. The Discharge Summary must include:

- a) General observations about the client's condition initially, during interventions and at discharge.
- b) Whether the discharge was planned or unplanned and, if unplanned, the circumstances necessitating the discharge.
- c) Assessment of progress toward the Therapeutic Integration Plan objectives and goals.

- d) Documentation of the summary sent to the CEDARR Family with recommendations for referral to other appropriate program or agency.

## **II. Monitoring and Quality Assurance**

Site visits will be conducted by DHS staff to monitor appropriate use of Medicaid services and compliance with the procedures outlined in this document. During these visits, staff will review the following:

- Client records and PASS Service Plan
- Staff orientation programs and attendance logs
- Agency policy and procedures related to TCYC service provision
- Claims information/documentation
- Staff time sheets
- Complaint log

Providers will be notified of DHS site visits in advance if possible. Unannounced site visits may also be conducted at the discretion of the Department. DHS staff may contact or visit families as part of the oversight and monitoring activities.

In the event of adverse findings of a minor nature, repayment to DHS will be required. In situations where, in the opinion of the Department, significant irregularities in billing or utilization are revealed, providers may be required to do a complete self-audit in addition to making repayments. In either case, technical assistance in developing and implementing a plan of corrective action, where appropriate and applicable, will be offered to the provider.

In addition to monitoring conducted by DHS, providers are subject to periodic fiscal and program audits by the Center for Medicare and Medicaid Studies (CMS).

## **III. Client Record Guidelines**

All PASS services must be provided in accordance with the PASS Service Plan that documents the medical necessity of the services. Plans for clients for whom PASS Agencies are billing Medicaid must conform to the following guidelines:

1. Each client shall have a current written, individualized PASS Services Plan that is based on assessments of the client's strengths and needs that precluded participation in the home or community without the support provided by the PASS Service Plan.
2. Responsibility for the overall supervision of the PASS Service Plan activities must be assigned to an appropriately qualified health care professional.

3. The Service Plan must be thoroughly reviewed at major decision points in each client's course of services including:
  - (a) The time of admission and discharge
  - (b) A major change in the client's condition
  - (c) At least every six months
4. The PASS Service Plan must contain specific goals toward which the client must progress, achieve and/or maintain. These goals must be based on periodic assessments of the prioritized needs of the client and family. These assessments occur through monthly meetings with Family Support Coordinator from the PASS Agency and family.

#### **IV. Supplemental Guidelines:**

1. Medicaid is, by definition, a medical program, which pays for medical services. The family, a Clinical Consultant and the Direct Service Workers must sign a PASS Service Plan.
2. The diagnosis must clearly be evident in the PASS Service Plan and the diagnosis must be considered as the overall plan is developed
3. The reasons for and types of assistance to facilitate participation and inclusion in the home and community setting should be evident in the plan.
4. Monthly progress notes should reflect a judgment being made by appropriate PA staff and the family regarding the results of the services rendered, i.e., an assessment of why the interventions are/are not working.